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ABSTRACT

Starting with the premise that all people have a right to quality health care, this guide emphasizes that assisting people with developmental disabilities to obtain health care and maintain healthy life styles will enhance the quality of their lives at home and in the community. The guide consists of four sections. A section on obtaining care describes some of the professionals and resource services that are available in the health care system. It discusses ways to be a more effective consumer advocate. The second section presents the basic steps in routine health care for children and adults, and discusses lifestyles or habits that contribute to good health. It explains how to prepare for a health appointment; the importance of having regular check-ups; and ways to stay healthy through nutrition, hygiene, dental care, injury prevention, and exercise. The third section focuses on coping with common illnesses and special health problems that frequently concern people with developmental disabilities. A section of resources lists 18 selected readings and 26 Minnesota organizations and programs. (JDD)

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Quality Health Care

For people with developmental disabilities

A GUIDE FOR PARENTS AND OTHER CAREGIVERS

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Preface

This health care guide is written for parents, advocates, helpers and friends who live and work with people who have developmental disabilities. Starting with the premise that ALL people have a right to quality health care, this guide emphasizes that assisting people with developmental disabilities to obtain health care and maintain healthy life styles will enhance the quality of their lives at home and in the community.

This guide contains four major sections:

1. being a more effective consumer advocate in selecting and working with health care providers;
2. managing routine health care, and developing healthy lifestyles;
3. managing common illnesses and more complex problems that affect the lives of individuals with developmental disabilities; and
4. finding resource materials and organizations of potential help in obtaining appropriate health care.

In informal language, basic information is presented on such daily routines as nutrition and hygiene, as well as on more complex considerations such as determining which subtle changes signal a need to call a doctor. While such information is pertinent to any individual concerned about health care, the emphasis in this guide is on how health care services, routines, and concerns relate specifically to the individual with developmental disabilities.

The information in this guide is presented with the hope that it will assist parents and other caregivers in obtaining and advocating for high quality health care for people with developmental disabilities.

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Introduction

Everyone values good health. When illness or injury occurs, we expect appropriate, professional health care and related services to be available reasonably close to where we live. We want doctors, nurses and other health professionals to be well-trained and compassionate people. We also increasingly recognize that we are responsible for making the kinds of lifestyle decisions that will help us maintain and improve our own health.

People with developmental disabilities—be they family members, neighbors, co-workers, or friends—have similar expectations and are entitled to the same health care as those who do not have disabilities. Due to physical or functional limitations, however, they may need special assistance to insure that their health care needs are met. Parents typically perform this role for their children. Adults with disabilities may also need to have an advocate to assist in obtaining medical treatment or care. With the current focus on alternative community living arrangements, it is likely that the advocate or helper will be someone other than a family member.

This guide to quality health care consists of four sections. The first section, on obtaining care, describes some of the professionals and resource services that are available in the health care system. It also discusses ways to be a more effective consumer advocate. The second section presents the basic steps in routine health care for children and adults, and discusses lifestyles or habits that contribute to good health. The third section focuses on coping with common illness and special health problems that frequently concern people with developmental disabilities. The final section lists resource materials and organizations that may be of help to you.

These guidelines are designed to help you—the parent, advocate, or helper—obtain appropriate health care for people with developmental disabilities. Improving the health of individuals with developmental disabilities will increase their ability to lead lives of dignity and purpose—both at home and in the community. You can make a meaningful contribution to that goal!

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I. Obtaining Health Care

Selecting Health Care Providers: WHOM to call WHEN

People with disabilities should have an established provider of routine health care, usually a primary care physician. Individuals with more complicated problems may need to see other types of specialists as well. The following section describes the various professional choices that are available.

Primary Care Specialists. Primary care physicians are generally your entry point to the health care system. Family practice physicians, pediatricians and internists usually provide primary care, which includes giving routine examinations and managing most health problems.

- **Family practice physicians** (formerly called "general practitioners") provide basic health care for people of all ages. Though their interests or experience may lead them to develop specific areas of expertise, they generally refer more complex problems to specialists.
- **Pediatricians and Internists** limit their practice to a particular age group; pediatricians to children and adolescents—internists to adults. These specialists often handle more complicated clinical problems.
- **Nurse Practitioners** usually work with primary care physicians, performing routine check-ups, treating minor illnesses, and providing health education. They are registered nurses with the additional education to provide many primary health care services.

Other Specialists. In addition to primary care specialists, there are those who specialize in particular areas.

- **Surgeons** limit their practice to surgery. They may specialize in working with particular age groups (children or adults) or performing particular types of surgery (e.g., heart surgery or bone surgery).
- **Obstetricians** specialize in delivering babies and caring for a pregnant woman before her delivery.
- **Gynecologists** specialize in women's health care, including evaluating the functions and treating the disorders that are unique to women.
- **Psychiatrists** specialize in the care of persons with mental disorders.

Subspecialists. There are physicians who treat disorders of a particular age group or anatomical type. For example, gerontologists treat elderly patients, and orthopedists treat disorders of the bones. Table 1 indicates the various levels and areas of specialization.

Though many people with developmental disabilities have routine health concerns that can be addressed by a primary care physician, they may also have complicated medical problems that need the attention of a specialist. For example, a person with a seizure disorder may need care from a neurologist, and someone with a heart problem may need evaluation by a cardiologist. Since many medical specialists do not provide routine health care, a person who goes to one or more specialists may go to a primary care physician as well. The referral to a specialist, usually made by the primary care physician, may also be initiated by parents or guardians if there is concern about a particular problem or a need for a second opinion. When multiple physicians are involved in a person's health care, it is important that they keep each other informed and that one provider acts as a coordinator.

Multi-specialty clinics and centers for people with developmental disabilities

- **Multi-specialty clinics** have many health care providers in one location including, in some cases, professionals who specialize in the care of people with developmental disabilities. Such clinics are especially valuable in facilitating the care of individuals who have multiple and/or severe health problems. Usually, these clinics are affiliated with universities, metropolitan health centers or large hospitals.
- **Referral hospitals** are specialty hospitals that are equipped to handle complicated problems such as corrective surgery or extensive evaluation and treatment. Frequently there are clinics affiliated with these hospitals where patients come for appointments, but

Table 1
Health Care Providers by Area of Specialization

Primary Care Specialists	Family Practitioner	Pediatrician (Children & Adolescents)	Internist (Adults)			
Other Types of Specialists				Surgeon	Obstetrician Gynecologist	Psychiatrist
Subspecialists						
Area of specialization*						
Eyes		Pediatric Ophthalmologist	Ophthalmologist	Eye Surgeon		
Nervous System		Pediatric Neurologist	Neurologist	Neurosurgeon		
Heart		Pediatric Cardiologist	Cardiologist	Cardiac Surgeon		
Stomach		Pediatric Gastroenterologist	Gastroenterologist			
Skin		Pediatric Dermatologist	Dermatologist	Plastic Surgeon		
Lungs/Chest		Pediatric Pulmonary Specialist	Pulmonary Specialist	Thoracic Surgeon		
Bones		Pediatric Orthopedist	Orthopedist	Orthopedic Surgeon		
Kidney/Urinary Tract		Pediatric Nephrologist	Nephrologist	Urologist		
Blood		Pediatric Hematologist	Hematologist			
Hormones and Hormone Secreting Glands		Pediatric Endocrinologist	Endocrinologist			
Allergies		Pediatric Allergist	Allergist			
Particular Age Group		Neonatologist (sick and premature infants)	Gerontologist (individuals who are elderly)	Pediatric or Adult		

*While most specialists limit their practice to pediatric or adult care, some see clients of all ages.

do not need to be admitted. These are called "outpatient" or "ambulatory care" clinics.

Other Community Resources

- **Community hospitals** typically care for individuals who are admitted for routine health problems and procedures.
- **County public health nurses** may be asked by physicians to make home visits to assist with medical procedures such as giving injections, changing wound dressings or providing health education. County public health nurses may provide case coordination for children with multiple chronic health conditions or for individuals with developmental disabilities who have extensive health problems. If you think any of these services are necessary, discuss the person's needs with an involved physician or call the county agency directly.
- **Psychiatric or mental health services** are provided by community mental health centers which are supported, in part, by public funds. All people have access to these services. The staff of these centers includes psychiatrists (physicians who specialize in the diagnosis and treatment of mental disorders), psychologists, and social workers. In larger communities, such professionals are also in private practice.

Keeping Records

An important part of your job in facilitating health care for a person with developmental disabilities is keeping accurate health records. Routine health care, appointments, dates of immunizations, episodes of illness, and prescribed medications should be included in the record. All records should be kept together in a safe place. These records will make your job of coordinating health services easier, and will assist anyone who might assume these responsibilities after you.

The records you keep need not be elaborate or time consuming. A record of appointments need only contain basic information, such as the date of the appointment, the name of the health care provider, the purpose for making the appointment, a list of your questions and any recommendations that the health care provider made. Table 2 is an example of an appointment record with sample entries.

Table 2

Health Care Appointment Record

Date of Appointment	Health Care Provider	Purpose for Appointment	Questions for Health Provider	Recommendations
9-9-87	Dr. Allen Neurologist	to check blood levels of seizure med.	• Complaining of tummy ache after taking medication • No staring spells	• Continue on same dose of medication • Take medication with food
12-18-87	Dr. Jones Pediatrition	routine check-up	• pulling on ears	• Right ear infection • Give antibiotics for 10 days • Return for re-check in 2 weeks

You may find it helpful to bring this record along when you go to a physician or other health care provider so you can fill in the information during the visit. You can also use it to record questions and answers. If medications are frequently prescribed or if there are long-term medications being used, you may want to keep a separate record sheet just for medications. Information that should be recorded includes the name of the medication, the physician who prescribed the medication, the dosage, when it was started and discontinued, and any noticeable affects. Table 3 is an example of a medication record with sample entries.

Table 3

Record of Prescribed Medications

Medication	Dosage	Date Started	Date Discontinued	Reactions/ Comments	Prescribed by:
Ethosuximide (for seizures)	1 tsp every morning	6-8-87		• May get drowsy or dizzy • Take with food to minimize abdominal pain	Dr. Allen
Amoxicillin (for ear infection)	1 tsp 3x/day	12-18-87	12-28-87	• May get diarrhea • Stop if rash develops	Dr. Jones

Being a Wise Consumer and Advocate

When you seek health care for someone with developmental disabilities, you are helping that person obtain a service—you are a consumer. As with other services or purchases, you should consider such issues as quality, price, and convenience.

Communication is one of the keys to good health care. You want a health care provider that you can talk to freely and one who listens to your concerns regarding the person with the disability. If you are having difficulty, discuss this openly with the provider.

Quality care is sometimes difficult to assess. Good communication is only one sign of clinical competency. Have specific expectations when you go to a physician or other health care provider. There are some generally accepted practices that are indicative of quality care. The basics of quality health care are outlined in the next sections. They are also presented in more detail in consumer-oriented guides to health care and in *Health Care Standards for Persons With Developmental Disabilities* (Nelson & Plumb). You will find references to these and other resources in the final section of this guide.

While convenience alone should not dictate your choice, you do want to consider whether a provider has both an accessible location and clinic hours that are convenient for your schedule.

Keep in mind that persons with developmental disabilities should receive the same quality health care as others. While some communities have developed well-organized systems for service provision, some persons with developmental disabilities do not have access to the care they need to maintain or restore optimal health. In part, your choices will be limited by your geographic location. In metropolitan areas there are typically more options than in rural areas. But even in areas where there are more providers, not all are trained or prepared to treat individuals with developmental disabilities. When you feel that your options as a consumer are restricted, you may need to become an advocate to remove the barriers blocking your efforts to obtain quality care for the individual with developmental disabilities. Organizations that can help you in this advocacy role are listed in the resource section of this guide.

II. General Health Maintenance for Children, Adolescents and Adults with Developmental Disabilities

Preparing for an Appointment

An important contribution to any visit to a health care provider is the advance preparation for the child, adolescent or adult about what will occur. Tell them where they are going, who they will be seeing, and what is likely to happen during the visit. For instance, tell them that they will be weighed and measured, that they will be asked to remove some or all of their clothing, and that the provider may use instruments like a stethoscope and reflex hammer during the exam. Be honest about things that might hurt or be uncomfortable. Let them know what will be expected of them and what they can do to help. If you are unsure about what might take place during the exam, ask the doctor or nurse at the clinic when you make the appointment.

Be sure to adequately prepare the staff at the clinic. Offer any information about the child, adolescent, or adult that you think would be helpful—for instance, explaining that the person concerned is most likely to be cooperative if approached in a certain way. Encourage professionals, whenever possible, to communicate directly with the person with a disability.

Finally, be prepared yourself. Make a list of your questions or the issues that you want to discuss. This will help you to organize and remember your concerns, will add structure to the visit, and will insure that all of your concerns are addressed.

Regular Check-ups

A regular check-up is one of the first things that comes to mind when we think of a "visit to the doctor". This periodic examination is a basic feature of health care. Since the frequency and content of these examinations is quite different for children and adults, these age groups will be discussed separately.

INFANTS, CHILDREN AND ADOLESCENTS

Infants, children and adolescents need to see a physician on a regular basis to monitor growth and development and to diagnose emerging problems. A key to reducing the adverse effects of developmental disabilities and other handicapping conditions, is to identify and treat illness, or the cause of the disability, early. EARLY INTERVENTION is a critical element in preserving and restoring individual capacities. Table 4 lists the recommended schedule for routine check-ups.

While the scheduling and frequency of some visits may vary, having a check-up at least five times in the first year of life, three times in the second, three times in the preschool years, and four times in the school and teen years is considered minimal for good care. Depending on the nature and severity of the child's health problems, such visits may need to be scheduled much more frequently. While certain acute problems such as colds or other infections may be evaluated at these times, the focus of regular check-ups should be on the health and developmental status of the whole child.

These health supervision visits should include the following activities:

1. A review and discussion of the child's **health history** since the last visit. This should include a discussion of the child's nutrition, sleep, and behavioral patterns; current stage of development; illnesses or accidents since the last visit; and any concerns or problems that you would like to discuss.

Table 4
Recommended Schedule for Routine Check-ups During Infancy, Childhood and Adolescence (American Academy of Pediatrics)

Infancy	Early Childhood	Late Childhood	Adolescence
by 1 mo	15 mo	5 yr	14 yr
2 mo	18 mo	6 yr	16 yr
4 mo	24 mo	8 yr	18 yr
6 mo	3 yr	10 yr	20 yr
9 mo	4 yr	12 yr	
12 mo			

2. **Height and weight measured and recorded**. These measurements should be recorded on graphs that show whether the child is growing within the normal range for his or her age. Children under three should also have their head circumference measured and graphed.
3. A complete **physical examination** of the child. This exam should include all parts of the body, from head to toe, with clothing removed. (Older children may prefer to leave their underpants on except during the genital examination.)
4. **Immunization** status should be assessed and immunizations given, if necessary.
5. A formal or informal assessment of the child's **developmental status**. This may be a discussion with you about the child's capacities and behaviors. For the young child (under five), when developmental changes occur rapidly, this assessment should also include developmental screening using a standardized procedure.
6. An assessment of the child's **vision and hearing**. Until the child is old enough to cooperate with the standardized testing (around 3 or 4 years), vision and hearing is assessed through informal screening. However, there are sophisticated ways to test even very young children. It is very important to identify and treat any vision or hearing impairments as early as possible; if you suspect a problem, ask for this type of evaluation. After age three or four, children should have their hearing evaluated with the use of a pure tone audiometer, and their vision evaluated with an eye chart.
7. Finally, you should receive **treatment recommendations** regarding such things as diet, medications, and a suggested time for the next visit. If instructions are long and/or complicated, ask to have them written out.

ADULTS

The benefit of an annual check-up for adults less than 40 years of age may be minimal. Unlike developing children who experience regular changes and can have emerging problems, an adult's health status is relatively stable. When there are new problems, they tend to be acute, brief and rarely coincide with a check-up. However, some adults with developmental disabilities who are unable or unlikely to communicate symptoms of a potentially major health problem may be an exception to this pattern. A thorough examination may reveal an unrecognized problem.

The current approach to check-ups for adults is that the frequency should depend on the age, sex and health status of the individual. While there can be no definite answer to how often someone needs a check-up, here are some general guidelines:

1. **People with chronic illness (i.e., seizures, allergies) need to be evaluated periodically**. The frequency depends on the stability and severity of the disease. People who are on long-term medication should be evaluated at least once a year. If you think the condition of an adult with a developmental disability has changed, you should request an evaluation, regardless of a scheduled appointment.
2. **All women should have a gynecological exam by the age of 18 and routinely, thereafter**. Sexually active women should have routine gynecological exams, regardless of age. (Specific information on gynecological exams will be covered in the next section.)
3. High blood pressure is a significant medical problem that has few outward symptoms. **All adults should have their blood pressure checked annually—more frequently if it is elevated (above 150/90 mm Hg)**.
4. Glaucoma is a treatable disease that can cause blindness. **People over 40 with a family history of glaucoma should have a screening test for this disease done every few years**.
5. **When you change physicians, it is a good idea to schedule a routine check-up with the new physician**. This is a good way for the physician and the patient to get to know each other. The new physician can also obtain valuable base-line information, prior to seeing the patient during an acute illness or in an emergency situation.

6. **When a complete examination is scheduled it should include**:
   - health history that includes past health problems as well as a review of current concerns you may have
   - head to toe physical exam
   - blood pressure check
   - glaucoma screening for individuals over 40, with a family history
   - vision and hearing screening
   - health education that would include, depending on client needs and interests, such topics as nutrition, exercise, accident prevention, breast self-examination or testicular self-examination
   - treatment instructions and recommendations
   - laboratory tests on blood and urine

WOMEN

Beyond the health care required for all adults, woman have a special set of needs that should be addressed routinely. These include screening for breast and uterine cancer, a pelvic exam (of the internal and external genitalia), and an assessment of menstruation. All women should have this type of check-up, called a gynecological exam, by the age of 18 (or earlier, if they are sexually active) and at least every three years after that. Many women should have a gynecological exam every year. These include women who have had abnormal cancer screening in the past, women using contraception, and all women 40 years of age or older. The exam may be done by a family practice physician, an internist, a gynecologist or a nurse practitioner.

Adequate preparation of an individual with a developmental disability is important before any appointment with a health care provider, regardless of the nature of the visit. However, with a gynecological exam—especially the first one—careful preparation can mean the difference between a relatively comfortable exam and a traumatic experience.

Before a gynecological exam, explain to the woman that she will be asked to take her clothes off, put a gown on, and lie on an examining table with her feet in stirrups (foot-rests that are attached to the examining table). Tell her that during the exam a physician or nurse will touch her breasts and genitalia and put an instrument (called a speculum) in her vagina. Be sure that the woman understands that it is appropriate for the physician or nurse to touch her in this way, and help her distinguish this from situations where it would NOT be appropriate.

Pelvic exams need not be painful, but they can be uncomfortable. A key to reducing any discomfort is for the woman to relax her abdominal and pelvic muscles as much as possible. Deep breathing and focusing her attention on something else (a picture, a light, or your face) can help her relax. Have the woman practice relaxation techniques before the exam. You should also use pictures, diagrams and/or a doll to explain the nature of a gynecological exam.

Take some time, as well, to prepare the physician or nurse who will be doing the exam. If this is a woman's first pelvic exam, tell the examiner. If it is a repeat exam, provide information on how she reacted to the previous exam(s). Let the physician or the nurse know how the patient likes to be addressed and what her level of understanding is. Request that the examiner talk to the woman and explain what he or she is doing throughout the exam. For some women with developmental disabilities, a careful gynecological exam may take additional time. Consider scheduling a longer appointment to accommodate these special needs.

A routine gynecological exam should include:

1. A review of the woman's **health history**. While the focus is on menstrual and reproductive history, the woman's general health should be considered.
2. **Height, weight and blood pressure** should be measured and recorded. Because blood pressure is a significant medical problem, with few outward symptoms, it is especially important that this be measured and recorded at every visit.
3. A **physical exam** should be done that, minimally, includes:
   - an exam of the head and neck, including the thyroid gland
   - an exam of the heart, lungs and abdomen
   - a systematic exam of both breasts and the surrounding lymph nodes
   - a pelvic exam of the internal and external genitalia
   - a rectal exam.

4. **Laboratory tests** should include:
   - a urine test (to determine if there is infection or other abnormality)
   - a blood test for hematocrit or hemoglobin (to detect anemia or iron deficiency)
   - a pap smear (taking a sample of cells from the opening of the uterus to check for cancer).
5. **Health education** on women's health issues should be given. Information should cover techniques on breast self-examination, reproductive physiology, birth control, and venereal disease prevention. While the scope of this information must be adjusted to individual client needs, these topics should be considered with EVERY woman, regardless of the type or extent of her disability.
6. **Contraceptive information** should be given to women who are sexually active, or potentially so, and who do not want to become pregnant. It is important that neither you nor the health care provider make the assumption that because a woman has a developmental disability, she does not need contraceptive information. There are numerous methods of contraception, from abstinence to sterilization. While a thorough discussion of contraception is beyond the scope of this document, you should expect a health care provider to review the various methods and their relative advantages and disadvantages. However, the health care provider may NOT be an expert on developmental disabilities or the needs, competencies and preferences of the woman. A final decision on contraception can only be made after all of these factors are considered. Both you and the woman with a developmental disability should be active participants in the discussions and in the decision. In certain situations —such as when sterilization is being considered—an advocate or a guardian MUST become actively involved in these discussions.
7. A **mammogram** is a type of X-ray of the breast used to detect cancer. This test should be done if the woman or the physician feels any masses, if there is discharge from the nipple, or if the breasts are difficult to examine. A mammogram should also be done on all women around the age of 35, and periodically thereafter. During a mammogram, the breast tissue is compressed between two plates and the woman must remain motionless. This procedure can be uncomfortable and it is important to adequately prepare the woman before the exam.

Staying Healthy

For individuals with developmental disabilities, as with all of us, the ability to maintain our health and well-being is frequently less dependent on a physician or other health care provider than on our own personal health habits. As health care becomes more scientific and technical, we are discovering that common sense measures may also maximize the functioning and life span of many individuals. A well-rounded diet, regular exercise, and simple injury prevention and hygiene measures are keys to staying healthy. While it may be more difficult for some individuals with developmental disabilities to implement these measures, they are no less important.

The role of healthy life styles in preventing a wide range of health problems, from tooth decay to heart attacks, is covered extensively by the media and has become a part of our culture. In the following discussion, some important information is highlighted.

NUTRITION

The basic nutritional components of the foods we eat are protein, fat and carbohydrates. Fiber is a non-nutritive element of foods.

Protein is made of amino acids—the "building blocks" for body cells. Foods such as meats, fish, eggs (the whites), and dairy products contain a high percentage of protein. Many vegetables and grains are also important sources of protein, although the percentage of protein that is in these foods is somewhat less than it is in meats, fish, and dairy products. While protein is an essential part of a balanced diet, the typical American diet often contains more protein than is needed. Unless someone is on a vegetarian diet, or a very restricted diet, they need not be concerned about getting enough protein.

Fat is another basic component of food. It is a concentrated form of calories and is often stored in body fat as an energy reserve. (One gram of fat has more than twice the calories as an equal weight of protein or carbohydrates.)

There are two basic types of fats: saturated and unsaturated. Saturated fats are those that are solid at room temperature (i.e., butter and animal fats, and coconut and palm oils). Unsaturated fats (i.e. vegetable oils) are those that are liquid at room temperature. Saturated fats raise the levels of cholesterol in the body, while unsaturated fats can actually help to lower it. Cholesterol is a substance related to fats that is also an essential nutrient. However, the typical American diet contains far too much saturated fat and cholesterol. This contributes to weight problems and to life-threatening diseases of the heart and blood vessels. A basic goal of good nutrition for older children and adults is to reduce the amount of saturated fats and cholesterol that they eat. While many of the health risks associated with high levels of fat and cholesterol, such as heart attacks and strokes, do not occur until adulthood, research suggests that there are health benefits to starting on a reduced fat and cholesterol diet early in life. Young children, however, (under the age of four) should NOT be on a reduced fat or cholesterol diet. They are still developing and a modest amount of fat is necessary for optimal growth.

Red meat, egg yolk, whole milk, cheese, butter, and ice cream are high in saturated fat and cholesterol. While it is not realistic to eliminate these foods, their intake should be kept to a minimum. For instance, limit red meat to three servings a week; use low fat milk; use margarine instead of butter; and limit the intake of egg yolks to three per week.

Carbohydrates are the third basic components in foods. Carbohydrates are an important source of energy and some also contain protein. Those include the simple carbohydrates found in sugar and the more complex carbohydrates, or starches, found in vegetables, dried beans and grains. A basic goal for good nutrition is to increase the amount of complex carbohydrates in our diet, because these foods are:

- low in fat and cholesterol
- a good source of most vitamins and minerals
- an adequate source of protein
- generally high in fiber

Fiber is plant material that cannot be digested. Fiber in foods adds bulk to our diets without adding calories. It is important to have adequate fiber in our diets because:

- it helps prevent constipation
- it reduces the risk of diseases such as cancer and inflammation of the colon (the large bowel)
- it aids in the elimination of fat and can help reduce cholesterol levels in the blood

Foods that are high in fiber include whole grain bread products, vegetables (especially raw vegetables), fruits that have pectin (such as apples and grapes), and some dried beans.

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Table 5 summarizes the basic components of foods, their function and sources, as well as dietary recommendations.

Simply stated, a sound nutrition plan for older children and adults is to:

- have complex carbohydrates be the primary food source
- eat a modest amount of protein
- eat as little fat as possible

Notice that this basic nutrition plan does NOT include vitamin supplements. Most people do not need extra vitamins, since they are supplied by the foods we eat. Taking vitamin pills, especially in large doses, is a waste of money and can cause serious health problems. If you have questions about vitamins, consult a physician or a nutritionist.

Table 5
Nutritional Components for Good Health

Basic Components of Foods	Nutritional Function	Food Sources	Dietary Recommendations
Protein	• builds body cells	• meats • fish • egg whites • dairy products • some complex carbohydrates	eat a modest amount
Fat	• energy reserve	• fat in meats • egg yolks • butter • oils	keep fat intake as low as possible (for individuals age four and over)
Carbohydrates	• energy source • complex carbohydrates are also a source of protein	Complex Carbohydrates • breads and cereals • dried beans and grains • vegetables Simple Carbohydrates • sugars	complex carbohydrates should be the primary source of food
Fiber	• adds bulk • helps prevent constipation and bowel disease • helps lower cholesterol	• whole grain foods • raw vegetables • fruits with pectin (apples and grapes) • dried beans	eat 2-3 high fiber foods each day

HYGIENE

The word hygiene is based on the Greek word *hygies* which means "healthy". Hygiene has come to mean a regular routine of personal care to help keep one's body clean and healthy. It includes caring for the skin, hair, nails, and teeth, as well as wearing clean, comfortable clothes. Good hygiene can help prevent infections and illnesses, and it is also important for a positive self-image and social acceptance.

There are some steps that make up a basic good hygiene routine. Everyone, at an appropriate age and in an appropriate setting, should be taught these simple procedures. Once a procedure is taught, however, do not assume that your job is done. It is a rare child who does not need to be reminded to brush teeth or wash hands. Some individuals may need to be supervised to make sure they are carrying out these activities routinely and properly. When an individual is unable to do any of these things for himself or herself, then someone else must provide the needed assistance.

1. Dental care, a basic part of personal hygiene, is described in detail in the next section.
2. Hand washing is a simple procedure, yet its contribution to stopping the spread of disease cannot be overstated. Diarrhea, hepatitis and food poisoning can often be traced to poor handwashing practices. Hands should be washed with soap and running water before meals, when handling food, after toileting, and after any activity which soils the hands.
3. The face should be washed with mild soap and water at least daily. If a face cloth is used, it should be rinsed with cool water after use, and then hung where it can air dry. Individuals should have their own face cloth and towel marked with their names, if necessary; and these should be changed at least weekly.

   If acne is a problem, there are many over-the-counter preparations that can be useful, but there are others that either do no good or actually make the acne worse. Before purchasing any acne soap or medication, check with a pharmacist or your physician.

4. Frequent baths or showers have become a standard in our culture. However, daily bathing is not always necessary. Less frequent bathing (e.g., once every two or three days) is recommended for infants, young children and for individuals with dry skin. However, when someone does not have a tub bath or a shower, a wash cloth (different from a face cloth) should be used to wash underarms, genitals, and in skin folds or creases. Drying the skin completely after bathing is important in preventing skin irritations and sores. In humid weather or when persons have excessive perspiration, talcum powder may be helpful to keep the skin dry. (NOTE: Diaper or talcum powder is NOT recommended for general use with babies because of the likelihood of their inhaling the powder. This can result in irritation or damage to the lungs.)

   Feet should be washed daily. Pay particular attention to drying between the toes to prevent fungal infections (such as "athlete's foot"). If foot perspiration or odor is a problem, a foot powder or deodorant is recommended.

5. Adolescents and adults should use an underarm deodorant or anti-perspirant daily.

6. Fingernails should be filed or trimmed weekly. Hangnails should be cut, rather than torn off, to prevent infection. Toenails should also be trimmed weekly; trim toenails straight across to prevent ingrown nails.

7. Hair should be brushed or combed daily. The recommended frequency for shampooing depends on the hair-type. Individuals with dry hair may only need to shampoo once or twice a week, while those with oily hair may need to shampoo daily. Conditioners and rinses can reduce tangles, but they may also make thin or oily hair look limp and dirty.

8. Clothes should be clean and fresh smelling. Socks and underwear should be changed daily. It is also important that clothes fit well, since clothes that bind or are uncomfortable can cause skin irritations and sores.

9. When girls or women are menstruating, pads or tampons should be changed about every four to six hours. While many women prefer tampons, there is an increased risk of toxic shock syndrome with their use. This is a rare but life-threatening infection. Symptoms include fever, rapid heart beat, very low blood pressure and, sometimes, loss of consciousness. Because it is associated with tampon use, especially highly absorbent ones, it is recommended that women use the least absorbent tampon that is effective and switch to the use of pads both at night and on days when menstrual flow is light. Changing tampons more frequently does not prevent toxic shock syndrome, in fact it may make a woman more susceptible. The recommended schedule of changing tampons approximately every four or six hours should be followed.

10. Most men must shave their facial beards daily to have a clean appearance and, in some cases, to avoid skin irritations. A cordless electric shaver is preferred whenever ease of use or safety is a concern.

DENTAL HEALTH

Dental health is an important but often neglected area of health care. Dental disease is one of the most frequently cited problems for people with developmental disabilities. The prevalence of dental problems among people with developmental disabilities may be due to:

- poor teaching or supervision
- physical limitations that make self-care difficult
- increased risk of gum disease with certain seizure medications

Dental disease such as cavities (holes in the tooth enamel), gingivitis (inflammation of the gums), and periodontal disease (destruction of the gums and bones that support the teeth) are very common. These problems can be prevented by following a simple, regular program of oral hygiene that includes:

- brushing teeth after every meal (or at least twice a day)
- flossing teeth once a day
- routine dental check-ups every 6 to 12 months

Teeth Brushing. Teeth brushing helps to clean the teeth and aids in keeping the gums healthy. A clean mouth also makes a person feel and look better. Ideally, teeth should be brushed after every meal. If this is not possible, once after breakfast and once before bed is adequate. Use a toothbrush that has soft bristles and a flat brushing surface. The toothbrush should be wet and a SMALL amount of fluoride toothpaste applied. Be sure that the person is brushing all tooth surfaces including the inside, outside and chewing surfaces. The tongue and the roof of the mouth should also be lightly brushed. Finally, the mouth should be rinsed with cool water.

Each person should have his or her own toothbrush. Brushes should be stored where they can dry, but do not touch other brushes. It is also recommended that tooth brushes be replaced every two to three months.

Special adaptations of toothbrushes may be needed for individuals with physical limitations. Toothbrushes that mold to any angle when held under hot water are available at many drug stores. Toothbrush handles can also be made oversized or longer, or an elastic strap can be added to make them easier to hold. Electric toothbrushes may also be helpful for individuals with a weak hand-grasp or limited movement.

If a person is unable to brush his or her own teeth, arrangements must be made for someone to assist. Electric toothbrushes are especially helpful in these situations.

Flossing. Flossing removes the plaque and debris between the teeth and at the gum line that brushing misses. It is an IMPORTANT (though often neglected) part of regular oral hygiene and is especially important in preventing gum disease. Flossing requires a good deal of fine motor coordination, even for non-disabled adults. Young children and many adults with physical limitations involving their hands or arms, will probably need assistance with flossing.

Water pics and mouthwashes can help to freshen the mouth, but they are NOT substitutes for brushing or flossing.

Dental check-ups. Beginning at about the age of three, a person should have routine dental check-ups every 6 to 12 months. This check-up should include a careful examination for decay or other dental problems, a thorough cleaning and polishing of the teeth, and periodic x-rays to assess development and detect problems.

In addition to these routine visits, you should call your dentist for an appointment if the following problems arise:

- complaints of tooth or mouth pain (contact a dentist as soon as possible)
- sores in the mouth that do not heal within four or five days
- bleeding gums
- unusual swelling of the soft tissue of the mouth or gums
- discoloration of the tissue
- an unusual or abnormal growth

Oral hygiene for people with dentures. Oral hygiene should not stop with the loss of natural teeth. Cleanliness of dentures and the soft tissue of the mouth are important for the person's comfort and health.

Dentures and removable partials should be brushed after each meal (or at least twice a day) to prevent mouth sores and "denture breath", and to remove stains. The dentures should be brushed with a stiff, hard bristled brush and rinsed under running water before being replaced in the mouth. The tongue should be brushed, daily, with a regular toothbrush. At least once a day the mouth—including gum ridges, the insides of the cheeks, and the roof of the mouth—should be wiped with gauze.

Dentures should be removed each night to give the supporting tissue a rest. When dentures are left out of the mouth for any length of time, they should be stored in lukewarm water to prevent drying and warping.

Oral care for persons with hepatitis. If a person has hepatitis (a type of viral infection), simple precautions need to be implemented to prevent its spread to caregivers and other members in your household. These include specific procedures for those assisting with dental care. If a person in your household has a known or suspected case of hepatitis, ask your physician or dentist about these procedures and teach them to all caregivers. (For a general discussion of hepatitis, see Section III of this guide.)

INJURY PREVENTION

Accidents are preventable injuries and should be an important concern for all of us. They can cause needless pain, permanent disability, and death. Nationally, preventable injuries are the number one cause of death in children (after one year of age) and adolescents, as well as a leading cause of death in adults. Some individuals with developmental disabilities may lack the knowledge, the judgment, or the physical capability to protect themselves from injury. When you are supervising a person who has a developmental disability, you must be constantly vigilant for objects or circumstances that could be a source of injury.

Since motor-vehicle accidents constitute the vast majority of preventable injuries and accidental deaths, the single most important safety precaution that you can implement is the consistent use of seat belts. Children ages five and younger should travel in seats that are specifically designed and tested for use in autos. In many states, seat belt use and child-restraints are mandatory.

The first step in injury prevention is to make a careful assessment of the ability of the person with developmental disabilities to judge and understand. All of your prevention efforts should revolve around what the child or adult can reasonably be expected to agree to and handle independently. While it is important not to have a low expectation of capabilities, when safety is the issue you should conservatively estimate what the person can handle. It is also important not to base

your decision on a single observation. Be sure to observe the person several times and in a variety of settings. For instance, if you have seen a child crossing the street safely once, do not assume that the child has that skill and can generalize to other streets or parking lots.

Each setting—be it a home, work-site, school or playground—has unique safety hazards. You need to systematically evaluate each of these settings for safety hazards and correct or remove them when possible, or provide adequate supervision. Several parenting books have detailed lists of common safety hazards in the home, with suggestions for "child-proofing". While adults with developmental disabilities have different capabilities and thus different vulnerabilities, analyzing the environment in this way is useful in many situations.

People in wheelchairs and those with braces, crutches or other assistive devices may be vulnerable to additional safety hazards. If, for instance, you are caring for a person in a wheelchair, take a tour of your house in a wheelchair. Are there shelves, furniture or sharp objects that could hit someone moving at a sitting level? Are there electrical cords that could be caught or perhaps frayed if a wheelchair rolled over them? In order to see all of the safety hazards, you need to adjust the way you look at things.

An additional safety concern is that persons with developmental disabilities may be more vulnerable, due to impaired functional abilities, to physical or sexual abuse and manipulation. Education, peer group activities, and monitoring are necessary to reduce this vulnerability.

EXERCISE

A regular exercise program is one of the most important health habits that a person can develop. Exercise can help people:

- increase strength and endurance
- lose weight and keep it off
- lower blood pressure
- lower cholesterol in the blood
- increase flexibility of muscles and joints
- sleep more soundly
- reduce stress
- maintain strong, healthy bones
- strengthen the heart muscle and increase lung capacity.

Everyone can benefit from an exercise program, not just those who are athletically inclined, young, or non-disabled. An exercise program for persons with developmental disabilities does, however, take more thought and planning. Most individuals will not exercise spontaneously or independently. You may want to start an incentive or reward program to encourage participation. Often you will need to supervise these activities. Also, the type of exercise chosen will need to fit with the capabilities and needs of the individual.

When planning an exercise program, you will want to think about desired goals. One goal might be weight control. When people want to control weight, they most often want to reduce body fat and maintain, and even increase, their muscle tissue. This cannot be accomplished by dieting alone. Regular exercise should be a basic part of any weight control plan. If weight loss is a goal, an exercise program should be designed to burn the maximum number of calories (either vigorous exercise for 15 to 20 minutes, or moderate exercise for 30 or more minutes) at least four to five times a week.

Even for individuals for whom weight control is not a concern, exercise can tone muscles, increase muscle strength, and improve the flexibility of joints. This can increase an individual's capacity for work and for recreation. Another important benefit of increased flexibility is that it helps protect the muscles and bones from injury. For individuals with decreased mobility, a regular exercise program is essential to maintain current capacities and to prevent such problems as contractures or skin sores.

Another basic goal of many exercise programs is to strengthen the heart and the lungs. This is achieved through doing aerobic exercise. These moderately strenuous exercises increase a person's breathing and heart rate to meet an increased demand for oxygen to the muscles. Activities such as walking, jogging, bicycling and swimming are aerobic. Aerobic exercise must be performed for 15 to 20 minutes three or four times a week to benefit the heart and lungs.

When planning exercise activities or a fitness program for individuals with developmental disabilities, first check with their physicians to see if there are any specific limitations. You will also want to consider the person's needs, capabilities, and interests as well as the time and facilities that are available. Beyond the

resources in your home, take advantage of community education, YWCA, YMCA and local park board facilities and organized activities.

No matter what the exercise program, keep a few basic rules in mind:

1. **Exercise should be regular**. Occasional sporadic exercise does not contribute to physical fitness and it can be dangerous. Infrequently exercised muscles and joints are vulnerable to strains and sprains.
2. **Start an exercise program slowly and build gradually**. Overdoing exercise early on can cause soreness or injury, and take the fun out of it.
3. **Exercise should be fun**! Most people have activities they enjoy that also happen to provide exercise. Try to build at least some of these activities into an exercise program. Enjoyment may come from the pride of walking a little further or faster than the day before, or from losing weight. Such elements as enjoyment and pride are an important part of helping an individual stay with an exercise program and gain the maximum benefit from it.

III. Managing Common Illnesses and Special Health Problems

Common Illnesses: How to Identify Them and When to Call for Help

An important task in facilitating health care for a child or an adult with a developmental disability, is being able to determine WHEN the person is sick, and IF he or she needs to be evaluated by a health care provider. These may not be straightforward tasks. First of all, the decision is usually based on "second-hand" information; it is not your "ache", "pain", or "fever", but someone else's. Also, the person may be unable to tell you that he or she does not feel well, or be unable to describe exactly what is wrong.

There are, however, general signs of illness; these signs usually involve a change. If you are alert to these, you can recognize many illnesses early in their course. Common changes are described in this section.

This section is meant to provide you with general guidelines for evaluating illness and for making decisions about when to call a physician or other health care provider. Consumer-oriented guides to health care, containing much more detailed information (several are listed in the resource list) are also available. While they do not give information that is specific to persons with a developmental disability, they are very useful resources. However, these too, provide information that is only meant to be a guide. **If you are concerned and feel you need to talk to a health care provider, CALL—regardless of the information presented here or in any other resource. Similarly, when you call a health care provider, you may be told that the individual does not need to be seen. If you are still concerned, say so. If you want to be reassured by having a health professional evaluate the person, say so. Because you know the person, you are in the best position to notice changes. Respect your own judgment.**

CHANGES IN TEMPERATURE

The normal body temperature is 98.6° F orally (99.6° rectally, and 97.6° axillary—taken in the armpit), although there are individual variations. When a person's temperature rises more than a degree above normal, it is a fairly reliable sign of illness. Unless the person has had some sort of heat injury (i.e., sunburn, sunstroke, heat exhaustion) it usually means an infection. However, a higher-than-normal temperature is a general symptom that occurs with many different types of infection. It could be caused by a cold, a bladder infection, an abscessed tooth, or some other condition. Other

Call a physician or health clinic when:

the person has an oral* temperature:

- above 102° F
- above 100° F with another obvious sign of illness
- above 100° F for three or more days
- below 95° F

or an elevated temperature:

- accompanied by a seizure or with a past history of seizures with elevated temperatures
- accompanied by a stiff neck and headache, especially in children
- accompanied by right-sided abdominal pain

*Adjust these temperatures by adding one degree if temperature is taken rectally; subtracting one degree if taken in the armpit.

symptoms need to be considered in order to pin-point the source of the elevated temperature.

An elevated temperature should be treated by increasing the fluid intake in order to prevent dehydration. You may also want to give aspirin or acetaminophen (i.e., "Tylenol" or "Datril") if the person seems uncomfortable. **However, children and adolescents should only be given acetaminophen. Do NOT give them aspirin.** Aspirin use by children and adolescents has been associated with an increased risk of Reyes syndrome, a rare but serious illness.

A BELOW normal temperature (95° F. or below) can be the sign of a serious illness that needs prompt attention by a physician, especially in infants and young children.

CHANGES IN APPETITE

While fluctuations in appetite are common, a marked decrease in appetite may indicate illness. A decreased appetite may also be accompanied by nausea or vomiting. Children may simply complain vaguely of a "tummy ache". Even when individuals lose their appetites, it is important that they continue to take fluids. If the person has nausea and perhaps vomiting as well, small amounts of clear fluids (one or two ounces per hour) are often tolerated best.

Refusing to eat can be a serious problem for infants, since they rely on breast milk or formula not only for nutrition, but as their principal source of fluids. They can rapidly lose weight and become dehydrated.

Call a physician or health clinic when:

- a baby under six months of age stops eating, has difficulty eating (i.e., sucking or nursing) and/or doesn't seem to be gaining weight
- a child who usually has a good appetite refuses food for a day and seems listless
- an older child or an adult refuses food or has a significantly decreased appetite for two or more days
- a child or an adult refuses (or is unable to keep down) FLUIDS as well as food for a day
- a baby under six months of age has vomiting (NOTE: Infants frequently "spit up" small amounts after feeding. This is NOT considered vomiting.)
- a child or an adult has vomiting that lasts for more than 48 hours
- a person has vomiting that is accompanied by dizzy spells and headaches or by right-sided abdominal pain

CHANGES IN AFFECT OR BEHAVIOR

A change in affect (mood) or behavior can be sudden and dramatic, or it can be subtle and gradual. While such changes are sometimes difficult to judge, they can be early signs of illness. For instance, you should suspect illness when a child (or an adult) who is usually good-natured becomes crabby, when someone who is usually talkative becomes quiet and listless, or when someone who is fairly active starts acting tired or groggy. Analyzing these changes requires that you know the person's "normal" behavior and are alert to any differences.

Call a physician or health clinic when:

- changes in affect or behavior are accompanied by other signs of illness
- you are concerned about changes in affect or behavior
- the person exhibiting changes in affect or behavior is taking medications

CHANGES IN APPEARANCE

Many of us have had the experience of just looking at someone and sensing that they are sick. Our hunch is most often based on the person's general appearance, especially his or her color. When someone is pale, flushed (red) or jaundiced (yellow), we sense that the person is not well, and we are often right. Rashes can also be a visible sign of illness.

Call a physician or health clinic when:

- the person is unusually pale
- the skin or the "whites" of the eyes have a yellowish color (the person is jaundiced)
- lips, fingernails or face are a bluish or purplish color

  (NOTE: This can be a sign of breathing or heart problems. If the person has this bluish color and is having difficulty breathing, call a physician IMMEDIATELY.)
- skin is flushed WITHOUT recent exercise
- a rash is accompanied by a fever
- a rash is itchy, painful or spreading
- the person has a rash and is taking a medication

CHANGES IN BOWEL OR BLADDER HABITS

Some sort of change in bowel or bladder habits is a fairly reliable indication of illness. This could be an increase or a decrease in frequency. It could also be the loss of bladder or sphincter control for someone who previously had control.

Diarrhea is the frequent passage of loose, liquid stools. It is a sign of bowel irritation. It is frequently (though not always) caused by bacteria or viruses. This infection can be easily spread to others. Hand washing and careful handling or disposal of any soiled clothing or bedding is especially important when someone has diarrhea. Loose bowel movements can be normal for infants, but liquid or watery ones are not. Diarrhea in infants and young children can be serious, since it may lead to dehydration.

Constipation refers to bowel movements that are hard, dry and difficult to pass. It can frequently be treated without consulting a physician. Usually increases in fluid, fiber and activity are all that is required. Constipation, however, is another change that needs to be monitored.

Incontinence refers to the loss of bladder control in a child or an adult who typically has good bladder control. It can be the sign of a bladder infection. Increased urinary frequency may also be a sign of infection. On the other hand, a decrease in urinary frequency, or in the amount of urine being passed, can be a sign of dehydration.

Call a physician or health clinic when:

- an infant under 6 months of age has diarrhea (3 or more loose stools in a 24-hour period)
- a child or adult has diarrhea for more than 24 hours
- the person has diarrhea accompanied by abdominal pain, fever or other obvious signs of illness
- the person has a bowel movement that is bloody
- the person voids only a small amount of urine that is dark yellow and strong smelling (i.e., concentrated)
- an infant or young child does not urinate for 4-6 hours
- an older child or adult does not urinate for 10-12 hours or more
- a child or adult has increased urinary frequency or complains of pain or a burning sensation when urinating
- a child or an adult who has had bowel or bladder control becomes incontinent
- the person has constipation accompanied by abdominal pain
- the person has constipation that does not respond to increased fluid, fiber and activity

  (NOTE: Constipation should NOT be treated with laxatives, suppositories or enemas without consulting a physician.)

CHANGES IN BREATHING

While people may have slight changes in breathing patterns with colds and fevers, rapid, noisy or difficult breathing usually signals problems that need prompt medical attention.

Call a physician or health clinic when:

- the person appears to have difficulty breathing
- breathing appears more rapid or labored than normal
- lips or fingertips have a bluish or purplish color (NOTE: This may also occur when someone is cold. If the person is NOT having breathing difficulty AND normal color returns when he or she is warm, you do not need to call a physician.)

INITIATE RESUSCITATION AND CALL 911 OR YOUR LOCAL PARAMEDICS WHEN:

- the person's airway appears to be blocked
- the person has stopped breathing

EVALUATING COMPLAINTS OF PAIN

In addition to the above changes, which are general signs of illness, a person may have specific complaints, especially of pain. Pain includes a variety of symptoms—from a toothache, to a sore throat, to joint pain. All complaints of pain should be listened to and evaluated carefully. Some individuals have a high pain threshold, or an unusual tolerance for pain. There can be instances of broken bones or burns with no complaints of pain. This means you must be watchful for subtle changes and take what may seem like a minor complaint seriously.

Headaches can occur with stress, after a head injury, or with other symptoms such as sore throats or fevers. Headaches are fairly common in adults and as long as they are not frequent or severe, it is appropriate to treat them with over-the-counter medications such as aspirin and acetaminophen. On the other hand, headaches in young children are rare and generally need to be evaluated by a physician. Except for minor bumps, all head injuries should be evaluated by a physician.

Ear pain is often a symptom of an ear infection. It needs to be evaluated by a physician and frequently needs to be treated with an antibiotic.

A **sore throat** is a common complaint that frequently occurs with other cold symptoms such as a runny nose or a cough. It can be due to the same virus that caused the cold. There is no cure for viral illnesses such as the common cold, although increased fluid intake, throat lozenges, or salt water gargles may relieve some of the throat pain associated with them. Some sore throats, on the other hand, are caused by the streptococcal bacteria (i.e., "strep throat"). This infection can and should be treated with antibiotic medications—both to relieve the symptoms and to prevent possible heart and kidney complications. Knowing the difference between a viral sore throat and a strep throat is not easy. A throat culture is needed for a positive diagnosis. If the person has a sore throat accompanied by a fever, swollen neck glands, enlarged and red tonsils, or white patches on the tonsils, you should contact a physician or health clinic so a throat culture can be done. Similar action should be taken if the person develops a sore throat after being exposed to someone with strep throat.

Tooth and jaw pain should always be evaluated by a dentist. Sores on the lips or in the mouth that do not heal within four or five days should, likewise, be evaluated by a dentist.

Stomach pains are fairly common in young children. They may be related to constipation, diarrhea, or sore muscles; or they may be the child's way of expressing stress. You should contact a physician if a child or adult has abdominal pain that is sharp or accompanied by nausea, vomiting or a fever.

Joint pains and muscle aches can occur with illness and fever or can be due to physical activity, especially if the activity is out of the ordinary for that individual. Consult a physician if the joint or muscle feels hot to the touch, if there is any swelling, or if there is a loss of movement in the joint or muscle because of the pain.

Special Health Problems

SEIZURES

Epilepsy is a developmental disability which occurs more commonly in persons with other developmental disabilities, especially individuals with mental retardation or cerebral palsy. There have been major advances in the medical care of seizures. The majority of individuals can now enjoy complete seizure control on medication. Some individuals require more than one anticonvulsant medication in order to have satisfactory control. There is a relatively small group of persons whose medications are not entirely successful in eliminating seizures.

The term "seizure" generally refers to an involuntary motor movement—with or without a loss of consciousness—that originates as an abnormal electrical discharge in the brain. Some seizures occur as the result of infection in the central nervous system. In other cases, no specific origin can be medically identified. What is observed during a seizure can vary from generalized jerking movements of the trunk and extremities, to very subtle motor activities, such as twitching of the lips or eyelids. Physicians and nurses may not be able to diagnose a seizure disorder without an electroencephalogram (EEG or brain wave test) to determine if abnormal electrical discharges coincide with the observed movements.

It is now possible—through measurement of blood samples—to monitor the medication prescribed for persons with seizures. This should be done periodically under the direction of a physician. Potential changes in health status or behavior may be related to anticonvulsant medications and when observed, should be reported to the responsible physician.

When a person has a seizure disorder, discuss with your physician the specific procedures to be followed when he or she has a seizure. These include proper positioning to prevent injury, to keep the airway open, as well as when to call the physician or paramedics. It is important to discuss emergency procedures AHEAD of time and to make sure that caretakers or staff at school, work place and home know them.

When a person is having a seizure, it is important to avoid moving him or her unnecessarily. To do so could cause harm to the person or to those trying to assist. You may need to remove furniture or other objects, or position the person away from them. When possible, place the person on his or her side to prevent the tongue or other objects from blocking the airway.

If a person is having his or her first seizure and no other specific procedures have been worked out, place the person on the floor, on his or her side if possible (this will help prevent the tongue or other objects from blocking the airway). Do NOT attempt to put anything in the mouth. Call your physician as soon as you can. If the seizure lasts more than 5 minutes, call 911 or your local paramedics. If the person is having difficulty breathing, try to clear the airway and call 911 or your local paramedics.

EMOTIONAL AND BEHAVIORAL PROBLEMS

Some persons with developmental disabilities have significant behavior difficulties which are potentially harmful to themselves or to others, or which functionally isolate them from others. Recognizing and managing these difficulties is important if the person is to live successfully in the community.

Some behavior problems may occur during an individual's adjustment to a new residence, work place, or other life experience. Other behaviors may result from disorders of perception or thought.

Carefully observing behavior difficulties and writing them down are the first steps in their evaluation and management. A skilled professional—a psychologist, neurologist, or psychiatrist—may have to become involved to establish an appropriate diagnosis and care plan. In severe cases, medications that alter moods or behavior may be prescribed. However, unnecessary or inappropriate use of medications should be avoided.

HEPATITIS

Hepatitis is an inflammation of the liver generally resulting from a viral infection. There are two common types of hepatitis. Hepatitis A is usually transmitted through gastrointestinal secretions and is most commonly contracted through ingestion of contaminated food. Hepatitis B, or serum hepatitis, is contracted through the use of contaminated needles and occurs most often in our society in individuals who are abusing drugs.

During the time when persons with developmental disabilities lived in large, crowded institutions, the occurrence of infectious hepatitis was not uncommon. The risk of contracting hepatitis is greatly reduced in less crowded living situations. Such measures as careful handwashing and hygienic food preparation are key elements in avoiding the disease.

Individuals who experience loss of appetite, nausea, vomiting, a rundown feeling or jaundice (yellow skin) should be examined by a physician to rule out the presence of hepatitis. If a member of your household has hepatitis, discuss with your physician the specific procedures to prevent its spread.

OBESITY AND OTHER NUTRITIONAL PROBLEMS

Inactivity and a diet high in saturated fat or calories can lead to progressive weight gain and obesity. Obesity, in turn, discourages physical activity and can result in other health problems. In almost all cases, a well-planned eating program and periodic exercise can eliminate severe obesity.

Other persons with developmental disabilities have the opposite problem, namely difficulty in maintaining weight. This may result from difficulties in chewing or swallowing, or from situations where behavior interferes with eating. Consistent weight loss should be reported to the person's physician, who can help find the cause.

Medications

Medications are chemical compounds that can exert powerful effects on the body. They can relieve the symptoms of illness, and even cure certain illnesses. In addition to these desired or therapeutic effects, medications can have side effects. For instance, some medications can cause allergic reactions. When doses exceed recommended amounts, many medications have toxic effects; some can even be lethal. There are also medications which may interact unfavorably with other substances, such as alcohol or another medication.

Whether a person is taking prescription or nonprescription medications, care should be exercised. Medications should always be administered according to directions.

Each time a medication is given, you should make sure it is the right dose, of the right medication, for the right person, at the right time.

While some individuals with developmental disabilities may be able to take their own medications, almost all will need some level of supervision. You should also make sure that medications are stored safely, preferably in a locked cabinet or box. Finally, you will need to decide whether the desired or therapeutic effects were achieved and if there were any side effects. You can do this by asking the person and by your own direct observation.

PRESCRIPTION MEDICATIONS

Whenever a physician prescribes a medication you should make sure that you understand:

- why it has been prescribed or what effects are desired
- how long it should be taken (NOTE: While a few medications are to be stopped when the symptoms of the illness go away, most are to be taken for a specific length of time.)
- whether side effects are possible, and what to do if side effects appear
- the dosage schedule (i.e., how much of the medication should be administered, how often and at what times each day)
- whether there are special administration directions (i.e., to take medications with food or on an empty stomach).

You should discuss the reason for the prescription with the physician, but you can get most of the remaining information from either the physician or the pharmacist who fills the prescription.

Be sure to administer the medication according to directions. If the medication is to be given periodically throughout the waking hours of the day, space the times evenly from "wake up time" in the morning to bedtime. This will help to maintain a consistent level of the medication in the bloodstream. Missed or late doses can cause this level to drop, reducing the medicine's effectiveness or possibly causing "withdrawal" symptoms.

Each time you administer a dose, check the bottle to make sure that it is the right medicine and that you know what the appropriate dosage is. Because you need to check this information each time, never transfer medicine to an unlabeled bottle. If you would like the medication in two bottles (one for home and one for work or school) ask the pharmacist to do this.

LONG-TERM DRUG THERAPY

Occasionally, individuals are put on a medication for an extended or indefinite period of time. For instance, individuals with seizure disorders may need to be on anticonvulsant drugs for a lifetime. However, that does not mean that they are on the same dosage, or the same medication, for a lifetime. Individuals who are on long-term drug therapy should be evaluated by a physician at least once a year. This usually includes a test to check the amount of medication in the bloodstream. More frequent evaluations by a physician are generally needed when new medications are started or when the dosage is changed. The dosage of many medications is determined by the weight of the person. Children who are going through a growth spurt, or any individual who has a significant weight change, should be evaluated more frequently. Remember to continue to observe for both therapeutic (desired) effects and side effects during the entire time the person is on the medication. If you notice any changes in the medication's effects, call the prescribing physician.

NONPRESCRIPTION OR OVER-THE-COUNTER MEDICATIONS

There is a wide array of medications that can be purchased without a prescription. Some can be very effective in relieving the symptoms of illness. Others have very little effect. Still others can have dangerous side effects, especially if used improperly.

Whenever purchasing or using over-the-counter medications you should:

- **Read the label carefully**. Product labels describe the intended use and possible side effects of the medication as well as when it should NOT be used (i.e., contraindications).
- **Avoid misuse of the medication**. Follow product directions including dosage, frequency of administration and when to discontinue use.
- **Watch for desired or therapeutic effects**. Is the medication working? Is it providing relief from symptoms? If it is working, don't get caught by "if some is good, more is better" thinking. Give only the recommended amount. If there is no, or very little, effect within 24 hours, you should discontinue the medication and contact a physician.
- **Watch for side effects**. All drugs have potential side effects. Some side effects are impossible to avoid. For example, an antihistamine may relieve nasal congestion, but it also makes most people drowsy. If side effects are severe, stop administering the medication.
- **Be aware that many medications can increase blood pressure**. This can be dangerous for individuals with high blood pressure (hypertension). As a general rule, check with a pharmacist or physician before administering any over-the-counter medication to a person with high blood pressure.
- **Read labels very carefully, especially if a person has a drug allergy**. Product names often do not indicate the drugs they include.

Many over-the-counter drugs are a combination of several medications. For instance, many cold medicines contain ingredients to reduce fever, suppress a cough and alleviate congestion. You may not need all of these ingredients. Select a medication that treats only the symptoms that the person has. Administering fewer drugs is preferable and may be less expensive.

If you have questions about whether you should buy an over-the counter medication to treat a particular symptom, or are wondering what is available or how to use a particular product, ask you pharmacist or physician.

When Hospitalization is Necessary

Having to stay in a hospital, even for a short period of time, can be a frightening experience for a child or an adult with a developmental disability. It can mean getting used to many new, unfamiliar people as well as strange or unfamiliar surroundings. In addition, hospitalization usually implies the person is sick or needs some medical procedure. Ironically, when someone is sick enough to need hospitalization, it is likely the time they are least able to adapt to new people and unfamiliar surroundings.

For these reasons, it is important for you to be with the person as much as possible throughout their hospitalization —but especially during the first day or two—to make the transition easier and to provide comfort and reassurance. Young children especially need to have their parents close by. Many hospitals are equipped to have a parent stay in the room overnight with the child. If the hospital does not provide these accommodations, you may want to request it. For a child or an adult, it is often helpful to bring a few familiar objects (i.e., favorite toys, books, pictures) from home.

Hospital staff—including nurses, doctors, lab technicians and aides—will all have a role to play in the patient's comfort level and recovery. However, they may not be familiar with the person's schedule, preferences or idiosyncratic behavior. Be sure to tell the staff what to expect and what they might do to provide care that is as close to a home routine as possible.

If the person has a communication problem, such as decreased language skills, a hearing impairment or hard-to-understand speech, you will be a vital link between that person and the staff. You may need to be present to help explain to the patient what is happening or to help the patient communicate to the staff how he or she is feeling.

You are important both to comfort the hospitalized child or adult, and to help the hospital staff be as effective as possible. When you can not be at the hospital, leave a phone number with the floor secretary where you can be reached.

Resources

SELECTED READINGS

General Health Care

Health care standards for persons with developmental disabilities. Richard Nelson and Deborah Plumb (1987).

A compendium of accepted health care practices for all age groups. While this document was written as a resource for health care professionals, sections may be a useful reference for organizations interested in advocating for high quality health care for persons with developmental disabilities.

Write: Minnesota Governor's Planning Council on Developmental Disabilities
300 Centennial Office Building
658 Cedar Street
Saint Paul, Minnesota 55155

Take care of yourself: A consumer guide to medical care (3rd edition). Donald M. Vickery and James F. Fries. Reading, Massachusetts: Addison-Wesley Publishing Company, Inc. (1986).

Provides information on choosing a physician, stocking a home pharmacy, avoiding medical fraud, and planning a fitness program. Also contains easy-to-follow decision charts describing how to treat over 100 types of minor illness and when to call a physician.

The lifetime health monitoring program: A practical approach to preventive medicine. Lester Breslow and Anne Sommers. *New England Journal of Medicine*, (March 17, 1977), 299:11, pp. 601-608.

This article proposes health goals for each age group, and suggests preventive services that should be responsive to these goals. A detailed list of services is provided for infants and older adults.

Child and Adolescent Health

Take care of your child: A parent's guide to medical care (revised edition). Robert Pantell, James Fries and Donald Vickery. Reading, Massachusetts: Addison-Wesley Publishing Company, Inc. (1984).

This is a companion volume to *Take care of yourself*. It contains 95 decision charts that focus on common health concerns of young children, specifying home treatment and when to call a physician. There are also sections on child development, immunizations and accident prevention.

Baby and child A to Z medical handbook. Miriam Stoppard. Tucson, Arizona: The Body Press, (1986).

Describes in detail more than 150 baby and child ailments. Tells what you can do for them and when to call a physician. Also includes first-aid and emergency instructions.

Chronic Health Problems and Disabilities

The chronically ill child: A guide for parents and professionals. A.T. McCollum. New Haven, CT: Yale University Press (1981).

A guide to understanding and caring for the child with a chronic illness.

Guidelines for families: Improving health care for children with chronic conditions. Alfred Healy and J. Arline Lewis-Beck. Iowa University Affiliated Program, (1987).

These guidelines were developed by parents of children with chronic conditions. It consists of lists of practical recommendations on identifying health problems, determining needs and services, participating in care, and advocacy.

Write: University of Iowa
Campus Stores
208 G.S.B.
Iowa City, IA 52242

$2.50 per copy

Reproductive Health and Sexuality

Sex education for individuals with developmental disabilities: An annotated bibliography. B. McKray, R. Chambers, and K. Green et al, University of Iowa, Division of Developmental Disabilities (1982).

Consists of a subject listing, an annotated bibliography, and two appendices prepared for use by educators, parents, health professionals and handicapped persons. Subjects listed include adolescents, contraception, genetic counseling, sex education programs, and sexually transmitted diseases. Both print and audiovisual materials are presented.

Write: University of Iowa
Campus Stores, Room 30
Iowa Memorial Union
Iowa City, IA 52242
(319) 454-2121

$5.00 per copy plus postage

A guide for teaching human sexuality to the mentally handicapped. (4th Edition). Planned Parenthood of Minnesota (1977).

This guide addresses educational content on anatomy, menstruation, intercourse, conception, pregnancy and birth, contraception, relationships, masturbation, rape, and venereal disease. Also contains lists of resource materials on each topic.

Write: Planned Parenthood of Minnesota
1965 Ford Parkway
St. Paul, MN 55116
(612) 698-2401

$3.50 per copy

A selected bibliography on sexuality, sex education and family planning for use in mental retardation programs. Planned Parenthood of Minnesota (1985).

The materials listed are for professional education and training, parent education and client education in the areas of reproductive health, birth control, sterilization, and general concerns. Although not all resources listed were designed specifically for persons with mental retardation, they can be easily adapted for this audience.

Write: Planned Parenthood of Minnesota
1965 Ford Parkway
St. Paul, MN 55116
(612) 698-2401

$3.50 per copy

When parents consider sterilization for their sons or daughters who are mentally retarded. Association for Retarded Citizens of Minnesota (1984).

This paper provides basic information and legal implications when sterilization is considered for individuals who have mental retardation. It also outlines the questions that should be carefully thought out when sterilization is considered.

Write: Association for Retarded Citizens of Minnesota
3225 Lyndale Avenue South
Minneapolis, MN 55408
(612) 827-5641

Dental Health

Caring for the disabled child's dental health. Bureau of health education and audiovisual services, American Dental Association (1982).

A guide for parents that addresses preventing dental disease through sound nutrition, daily oral hygiene, making teeth more resistant to decay, and professional dental care.

Write: Continuing Dental Education
SC-62
University of Washington
Seattle, WA 98195
(206) 543-5448

$9.70 per copy

A manual of oral hygiene for handicapped, aged and chronically ill patients. Marathon County Health Department (1983).

A basic reference for staff members providing care in residential facilities that addresses dental health, dental hygiene, toothbrush adaptations for people with physical impairments, cleaning and maintaining dentures, and additional resources.

Write: Dental Hygienist, Marathon County Dental Health Project
Marathon County Health Dept.
400 East Thomas Street
Wausau, WI
(715) 848-1406 or
1-800-472-0082

Nutrition

Nutrition for children with special needs: For parents, teachers, aides, volunteers and the health care professional. United Cerebral Palsy of Minnesota, Inc. (1985).

Provides information on specific nutrition problems related to handicapping conditions and on feeding skill development and texture foods, provides list of resources and offers teachers ideas for nutrition education in special children.

Write: United Cerebral Palsy of Minnesota, Inc.
233 South Griggs Midway Building
1821 University Avenue
St. Paul, MN 55104
(612) 646-7588

$6.00 per copy for professionals
$3.00 per copy for parents

Jane Brody's good food book. Jane Brody. New York: W. W. Norton Company (1985).

Extensive, clearly written information on the basic components of food, nutritional recommendations, and weight control. Emphasizes high carbohydrate foods. Includes a recipe section.

The parents guide to nutrition. Boston Children's Hospital with Susan Baker and Robert Henry. Reading, Massachusetts: Addison-Wesley Publishing Company, Inc. (1987).

Covers basic issues of nutrition during infancy and childhood, including components of foods, vitamins, minerals, special diets, breast feeding, and infant formulas.

Exercise

An introduction to fitness with persons who are disabled. Christopher Roland and Larry Partridge (Eds.). Loretto, MN: Vinland National Center.

A manual designed to encourage persons who are disabled, as well as health care, recreation, and educational professionals to implement or expand fitness training programs. Information is presented on principles of exercise and various fitness activities. Basic techniques for fitness activities are outlined and specific activities are suggested for specific disabilities.

Write: Vinland National Center
P.O. Box 308
Loretto, MN 55357

Community recreation and persons with disabilities. Stuart J. Schleien and M. Tipton Ray. Baltimore, MD: Paul H. Brooks Publishing Co., (1987).

Discusses strategies to integrate the person with disabilities into community recreation programs including ways to overcome obstacles to participation, solutions to typical problems, and procedures for program evaluation. Also contains an annotated bibliography on current and relevant literature.

COMMUNITY RESOURCES

Organizations

Alternatives for People with Autism
5624 73rd Avenue North
Brooklyn Park, MN 55429
(612) 560-5330

Association for Retarded Citizens Minnesota (ARC)
3225 Lyndale Avenue South
Minneapolis, MN 55408
(612) 827-5641
MN toll free 1-800-582-5257

Community Health Education Network (CHEN)
3225 Lyndale Avenue South
Minneapolis, MN 55408
(612) 827-5641
MN toll free 1-800-582-5257
(Provides information on health and obtaining health care services for persons with mental retardation to parents and direct service providers. Also maintains a lending library.)

Epilepsy Foundation of Minnesota
672 Transfer Road
St. Paul, MN 55114
(612) 646-8675
MN toll free 1-800-292-7932

Legal Advocacy for Persons with Developmental Disabilities
222 Grain Exchange Building
323 Fourth Avenue South
Minneapolis, MN 55415
(612) 338-0968
MN toll free 1-800-292-4150

Minnesota Association for Persons with Severe Handicaps
P.O. Box 1837 Pioneer Station
St. Paul, MN 55101

Minnesota University Affiliated Program on Developmental Disabilities
6 Pattee Hall
150 Pillsbury Drive S.E.
Minneapolis, MN 55455
(612) 624-4848
(Training, technical assistance and continuing education for personnel working with individuals who have severe and profound developmental disabilities).

National Center for Youth with Disabilities, Adolescent Health Program
Box 721 University of Minnesota Hospital and Clinics
Harvard Street at East River Road
Minneapolis, MN 55455
(612) 626-2825
(Technical assistance and computer-based resource library for professionals and agencies, serving adolescents with chronic illness and/or disability.)

Parent's Advocacy Coalition for Educational Rights (PACER)
4826 Chicago Avenue
Minneapolis, MN 55417
(612) 827-2966

Twin City Society for Children and Adults with Autism, Inc. (TCSAC)
253 East Fourth Street
St. Paul, MN 55101
(612) 228-9074

United Cerebral Palsy of Minnesota
233 South Griggs Midway Building
1821 University Avenue
St. Paul, MN 55104
(612) 646-7588

Public Programs

Governor's Planning Council on Developmental Disabilities
Minnesota State Planning Agency
300 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155
(612) 296-4018
(612) 296-9962 (TTY)

County Public Health Nursing Agencies
For information, contact your local county offices, or
Section of Public Health Nursing
Minnesota Department of Health
717 Delaware Street Southeast
Minneapolis, MN 55440
(612) 623-5468

Medical Assistance Program
For information, contact your local county human services office, or
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
(612) 296-3386
MN toll free 1-800-652-9747
ext. 6-8822

Minnesota Department of Human Services
Division for Persons with Developmental Disabilities
444 Lafayette Road
2nd Floor
St. Paul, MN 55155
(612) 296-2160
(Monitors community-based services and approves medical assistance support for persons with mental retardation.)

Minnesota State Council on Disability
208 Metro Square Building
Seventh and Robert Street
St. Paul, MN 55101
(612) 296-6785 (voice or TTY)
MN toll free 1-800-652-9747

Service Resources

Children's Hospital of St. Paul
345 North Smith Avenue
St. Paul, MN 55102
(612) 298-8888

Comprehensive Epilepsy Program
2701 University Avenue Southeast
Minneapolis, MN 55414
(612) 331-4477

Courage Center
3915 Golden Valley Road
Golden Valley, MN 55422
(612) 588-0811
(Rehabilitation and independent living services for children and adults with handicaps.)

Gilette Children's Hospital
200 University Avenue East
St. Paul, MN 55104
(612) 291-2848
(Health care center for children and adults with disabilities.)

Minneapolis Children's Medical Center
2525 Chicago Avenue South
Minneapolis, MN 55404
(612) 863-6100

Polinsky Medical Rehabilitation Center
Pediatric Services
530 East Second Street
Duluth, MN 55805
(218) 727-5052

St. Paul Rehabilitation Center
319 Eagle Street
St. Paul, MN 55102
(612) 227-8471

Shriner's Hospital for Crippled Children
2025 East River Road
Minneapolis, MN 55414
(612) 339-6711

University of Minnesota Rehabilitation Center
420 South East Delaware Street
Minneapolis, MN 55455
(612) 626-3696
MN toll free 1-800-462-5301

Vinland National Center
P.O. Box 308
Loretto, MN 55357
(612) 479-3555
(Healthsports, health promotion and life-enhancement activities for individuals of varying ability.)

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